

**Lyme Disease Advisory Committee Meeting
Minutes of the March 25, 2003 Meeting
Department of Health Services Sacramento, CA**

The ninth meeting of the Lyme Disease Advisory Committee (LDAC) was held on March 25th, 2003, in Sacramento, California.

Committee members in attendance

Victoria Deloney, Ph.N., Sacramento County Public Health
Vicki Kramer, Ph.D., California Department of Health Services
Peggy Leonard, Lyme Disease Resource Center
Lee Lull, Lyme Disease Support Network
Susie Merrill, Lyme Disease Support Network
James Miller, Ph.D., University of California, Los Angeles
Scott Morrow, M.D., California Conference of Local Health Officers
Christian Parlier, Lyme Disease Support Network
Raphael Stricker, M.D., California Medical Association

Committee members not in attendance

Robert Lane, Ph.D., University of California, Berkeley

Other attendees

Anne Kjemtrup, D.V.M., Ph.D., California Department of Health Services
Peter Mackler, California Department of Health Services
Mark Starr, D.V.M., M.P.V.M., California Department of Health Services
Approximately 30 people representing the interested public and public agencies

I. Opening comments and review of minutes

Mr. Christian Parlier was announced as the new chairman of the LDAC.

Peter Mackler from the California Department of Health Services (DHS) Director's office congratulated Mr. Parlier, and welcomed the Committee and audience. He reviewed the Governor's veto message for SB 2097 and noted that with a budget deficit of an estimated 36 billion dollars, the Governor found it difficult to support any legislation that would require additional resources. The Governor gets information reflected in the veto statement from the bill itself, the bill's author, and his staff. Mr. Mackler announced that the Department of Finance has recently issued a directive to all State departments, limiting all non-legislatively mandated advisory committee meetings to one time per fiscal year. Thus, for FY 2003-2004, the LDAC will meet only one time. Because of expenses associated with meetings, the one time per year requirement is in effect regardless if members serve without travel reimbursement.

The minutes from the November 14, 2002 meeting were approved by the Committee on March 14, 2003 and will be posted shortly on the DHS web site (<http://www.dhs.ca.gov/ps/dcdc/disb/disbindex.htm>).

II. DHS progress report (Dr. Anne Kjemtrup)

Dr. Kjemtrup presented DHS accomplishments in four major goal areas of education: medical community, general public, school children, and risk assessment. A brief overview of DHS tick-borne disease surveillance activities was also given.

Briefly, the Physician Knowledge Assessment appeared in the February 1 Action Report, resulting in 286 responses. A brief update on the response level and a reminder about nymphal tick season will be published in the April 1 Action Report. A DHS representative attended the California School Health Nurse Conference in Los Angeles and distributed brochures to the nurses. The tick warning posters were printed and will be sent to local VBDS offices and agencies. Over 5,000 Lyme Disease (LD) brochures were distributed from the Vector-Borne Disease Section (VBDS) to physicians, nurses, health agencies, other government agencies, preschool and early childhood educators, LD support group leaders, and the general public. Presentations on vector-borne diseases, including Lyme disease, were given by VBDS staff to the United States Forest Service, Pest Control Applicators, and at the Mosquito and Vector Control Association of California annual conference. Tick surveillance, and in some areas tick testing for *Borrelia burgdorferi*, was performed by VBDS staff in Shasta, Butte, Placer, Sonoma, Napa, Santa Cruz, Riverside, Los Angeles, and San Bernardino counties.

In response to a Committee member's question, Dr. Kjemtrup stated that getting data from ticks that are recovered from people and that are tested for *B. burgdorferi* is an ongoing project and will be posted on the website when completed.

III. Update from the reporting subcommittee (Dr. Ray Stricker)

Dr. Stricker presented the activities of the reporting subcommittee that met twice (January 27, 2003 and March 3, 2003) via teleconference. Members of the subcommittee are Dr. Stricker, Ms. Leonard, Dr. Morrow, and Dr. Kramer. Drs. Mark Starr and Anne Kjemtrup of DHS sat in on both meetings.

Dr. Stricker reviewed the differences between passive, laboratory, and active surveillance and the process of the current passive surveillance system in California. He also reviewed data presented at the meetings regarding LD surveillance systems in Connecticut, Massachusetts, Minnesota, and Maryland. In addition to passive surveillance, all four of these states have laboratory surveillance systems for LD. CT and MA also have active surveillance systems. Only Maryland had a local-level primary evaluation of cases system similar to California, while in the other states, case reports were evaluated at the state level.

Dr. Stricker described a proposed LD laboratory surveillance system in California whereby a positive LD test would be reported to the local health department (LHD), and this would stimulate the LHD to follow up with the physician who ordered the test to get a case report. As with passive surveillance, primary evaluation of a case report would occur at the LHD. Making LD laboratory reportable will require a change in Title 17 regulations, a process that usually takes 1.5-2 years. The subcommittee also considered an active surveillance approach whereby participating physicians in California would anonymously report newly diagnosed cases of LD in California, and provide demographic information on these cases (e.g. sex, age, potential exposure in California or not). Dr. Stricker performed a small pilot study of 9 physicians and found that of the 6 who responded for November 2002, 22 new LD cases were

diagnosed and 17 (77 percent) of these were exposed in California. The subcommittee therefore recommended:

- Mandatory laboratory reporting of positive LD tests to DHS.
- Establishment of sentinel physician program for active surveillance of LD.

Dr. Mark Starr pointed out that changing the status of LD to laboratory-reportable would require a change in regulations (lengthy process) or the Health Officer Association of California (HOAC) could potentially encourage a legislative change whereby DHS could modify the reportable disease list without going through the regulatory change process. Active surveillance is already in place for other diseases; it is important to work with DHS in developing the active surveillance system so that a “our numbers” vs. “their numbers” problem does not occur.

The motion to accept the subcommittee recommendations was made by Dr. Miller, seconded by Ms. Lull, and passed unanimously by the Committee.

IV. Physician education

A. Concerns about the California Medical Association (CMA) position on Lyme Disease (Ms. Lee Lull)

Ms. Lee Lull presented a packet to the Committee describing information on LD provided to the CMA from a member of the CMA’s Scientific Advisory Committee, who is also a DHS employee. Ms. Lull expressed concern about DHS’ role in providing the information, presumably to be used by CMA in policy development. The packet contained summaries of: the issues Ms. Lull wished to address on the CMA policy development and DHS physician education material, the memo from the CMA with four questions and answers on LD addressed by the CMA’s Technical and Scientific Advisory Committee, and proposed letters to DHS from the LDAC addressing these concerns. A major concern was that physicians who serve on the CMA advisory committees and who are also employed at DHS are representing viewpoints about LD that have not been discussed with the LDAC.

It was pointed out that many professionals at DHS serve on outside committees in their professional capacity, not as representatives of DHS. Thus, opinions expressed by these individuals are their professional opinions. DHS does not have any authority over CMA, thus letters to DHS on CMA’s position on LD will not impact CMA.

Most, if not all, vector-borne disease questions are directed to the Division of Communicable Disease Control (DCDC) which houses VBDS. Dr. Kramer suggested that she could send out an email to key programs in DHS reminding people that the LDAC exists and questions on tick-borne diseases should be directed to VBDS. Also, it was suggested that Dr. Kramer could find out how a DHS physician not in DCDC was contacted by CMA about LD.

A motion was made by Dr. Morrow and seconded by Ms. Leonard for the LDAC to write a letter to the CMA Scientific Advisory Subcommittee to express concerns about the responses to the questions posed to the subcommittee, ask how the answers to the

questions would be used to develop a position statement, and let the CMA know that the LDAC exists. Dr. Kramer pointed out that it was not clear that LDAC, as an advisory committee to DHS, could write a letter to another agency. Dr. Morrow volunteered to draft a letter for the LDAC chairperson, Mr. Parlier, to sign. The motion was passed unanimously with Dr. Kramer abstaining.

B. Article for HMO newsletters

Dr. Kjemtrup presented a draft of an article that would be offered for HMO newsletters distributed in California. Three HMOs had been contacted to date and all three expressed interest in at least considering such an article.

In a response to a question on the inclusion of *Babesia* or *Bartonella* in the article, Dr. Kjemtrup noted that in the western United States, *Babesia* has not been found in *I. pacificus* and the vector for the WA-1 type *Babesia* remains unknown. While *Bartonella* has been found in *I. pacificus* ticks, vector-competency has not been proven for *I. pacificus*. Since the purpose of the article is to make people aware of *I. pacificus* tick activity (either in winter or spring), only diseases known to be carried by this tick were included in the article.

Other suggestions for the article included pointing out that tick ecology in the western U.S. is different from that of the eastern U.S. and mentioning coinfections. Suggestions will be considered and a revised draft will be sent to the committee.

An additional suggestion was offered to distribute press releases to LD support group leaders. It was confirmed that once the press statements are released by the DHS Office of Public Affairs, they can be made available to support group leaders.

C. Local health officer information

Dr. Kjemtrup presented a draft of an increased nymphal tick activity information paragraph that could be sent by email distribution to all health officers in California.

Comments included adding a statement to request health officers to include this information in bulletins for local physicians and to mention coinfections. Suggestions will be considered and a revised draft will be sent to the committee.

V. Next LDAC meeting

The next LDAC meeting will not be scheduled until the next fiscal year. VBDS is moving to a new facility in downtown Sacramento in July and meeting room availability is unknown at this time. Thus, the next meeting will be announced at a later date.

VI. Public comment

Dr. Herb Dorkin: Dr. Dorkin said that he was a legislative advocate for the Lyme Disease Resource Center. He spoke on Assembly Bill (AB) 1091. He felt that the Governor was misinformed about SB 2097 in 2002 and cited the criticism that the bill

would have expanded the LDAC to 10 members but, at the time it was vetoed, there were 10 members on the Committee. AB 1091 focuses on the composition of the LDAC, specifies the expertise of each appointee, and sets a rotating three year term limit. The long legislative intent section at the beginning of the bill is to serve as an informational brochure because very few people in the legislature are aware of LD. Dr. Dorkin's concern about the laboratory reporting approach mentioned during the meeting was that if it goes through the local health authority, it becomes a state-mandated program, and this could add cost. He feels that once there is more complete reporting, it will be evident that LD is not rare at all. Dr. Dorkin received a letter from the CMA advising him of the CMA's new policy in regard to the CMA representative on the LDAC. He mentioned that there seemed to be an inconsistency in treatment approaches and compared LD treatment to tuberculosis treatment where one can get treated for an 18 month period twice. He emphasized the importance of education of physicians, nurse practitioners, and HMOs about LD to avoid the problem of people not getting treated in a timely manner because their physician did not know about LD.

Wendy Ramage: Ms. Ramage described her experience as a chronic LD patient. She is currently in her 9th month of treatment for LD and coinfection. Her symptoms began in 1999 when living in Sonoma County. She became severely ill in 2000 and was finally diagnosed in July 2002. She had seen over 30 physicians. She never had the bulls-eye rash and was misdiagnosed three times. LD has involved profound suffering, loss, and fear. She was doing well in a clinical graduate program out of state when she finally became so ill she was forced to give up the program and return to her family in Sonoma County. She is extremely thankful for the physician who is treating her aggressively for the disease and the progress is immeasurable. She therefore has deep concern over the pending statement from CMA because long-term treatment has given her a second chance at living her life and has given her hope that she will have some measure of control over this disease in the future. She believes the CMA statement will deny people not only the treatment they need, but deny them hope for the future.

Terry Charonnat: Ms. Charonnat offered some suggestions on information distribution. She emphasized that school, local, and hospital libraries are key places to distribute information. She suggested that email distribution to all people required to get any kind state license in California (e.g. teachers, preschools etc..) would be helpful. A poster, perhaps designed as the result of a school-children's contest, could be hung at state agencies such as the DMV. Some kind of slogan would be useful as well. She emphasized that Kaiser is an important HMO to contact. She shared a newsletter in which she had written an article on LD and mentioned that it was important to direct people to use the internet where they can get a lot of information on LD.

Mark LaFevers: Mr. LaFevers suggested it is a positive step to make it clear who is behind statements and actions in the minutes of LDAC meetings because one issue that many Lyme patients are curious about is what is behind the pressures of public statements. He is supportive of mandatory laboratory reporting because that might take the burden away from shy physicians who do not want to report or treat Lyme patients. He struggled over 5 years and with 5 doctors to find out what was ailing him. The physician awareness issue in the Santa Barbara area is still a problem. The faster the education program gets going the better. Regarding the CMAs guidelines, he would

have been disabled if he had not been on oral antibiotics for over 1.5 years. He has experienced improvement.

Chris Pope: Mr. Pope has had Lyme disease for 4 years and has been treated continuously for the past 3 years. Because it took so long to diagnose and treat this disease, he is now on SSDI. He is now close to feeling human. He emphasized that so much more needs to be done because there are some very strong voices that say that LD is well-defined, easy to detect, hard to catch and easy to cure. None of that is true. As a scientific researcher, he is amazed at the strength of these voices.

Carol Martin: Ms. Martin made available an education packet on LD from the Torrington area health district. Her goal is to educate school children from K-6th grade about LD. She is working with the California PTA and has provided information for PTA resolutions and for AB 1091. She urged DHS that, in addition to the LD brochure, they have more information on LD available at the PTA convention. She said that it would be helpful if a simple webpage name could be developed for DHS Lyme education material. She asked for DHS to consider Saturday meetings if only one face-to-face meeting per year was going to be allowed.

Meeting adjourned 4:00 p.m.